



HDNL 2016 - Issue No 70, Q3 17

CHECK OUT OUR WEB SITE

www.huntingtons.ie

SUPPORT MEETINGS

See dates on page 4

GENETICS

For information on Genetic testing, contact the Genetics Centre. Tel: **01 409 6902** and www.genetics.ie

ENROLL HD

You can express your interest in participating by emailing enrollhd@beaumont.ie

Enroll-HD A worldwide observational study for Huntington's disease families

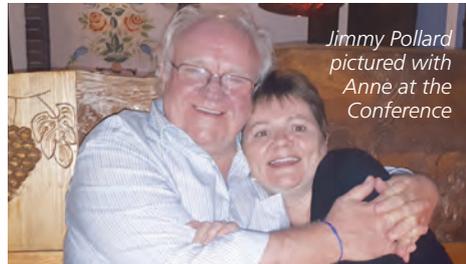
NEWSLETTER OF THE HUNTINGTON'S DISEASE ASSOCIATION OF IRELAND

Hope

IRELAND

EHA Conference

The European Huntington's Association Conference '**Stronger together**' took place in Sofia, Bulgaria from 22nd to 24th September. Anne and Dee attended as HDAl representatives and provided a report.



Jimmy Pollard
pictured with
Anne at the
Conference

The Conference commenced with an overview of HD Services in Bulgaria from the perspective of a family member, a neurologist and a health care worker. The Bulgarian HD Association was established in 2014. Challenges for HD in Bulgaria include: a lack of information on and experience of HD, a lack of awareness among the general population, absence of good practices, absence of clinical trials, a lack of specialists outside of the capital Sofia and the absence of specialised centres and HD long term care facilities.

A summary of a selected presentations from the conference are outlined below.

Dr. Alzbeta Muelhbaeck, Neuropsychiatrist discussed genetic testing. Whether it is best to take a predictive test or not is a personal choice and should not be entered into lightly. She suggests that it is advisable for anyone undertaking the test to educate themselves on the implications of a test result including implications on the decision to have children.

Dr. Ferdinando Squitieri and **Dr. Ralf Reilmann** gave an overview of clinical trials and why it takes so long for any trial to start and reach its conclusion.

- Compounds can take many years to develop
- A protocol must be written prior to commencing a trial
- Human safety trials are run with a small number of participants to test the safety and tolerability of the drug

- If there are no safety issues then an expanded safety trial is conducted. Participants are chosen by randomisation, some receiving the drug and others receiving a placebo
- If treatment is successful, all participants will receive the drug
- Trials can be double blinded - neither patients or doctors know who is getting the drug
- Researchers are looking for treatments to positively alter the course of the disease. Treatment must really benefit patients, there must be more pros than cons.
- Approval of the drug is then sought and finally marketing of the drug.

Each stage can take from months to many years. Trials must show new treatments are better than existing treatments. Dr. Squitieri and Reilmann stressed the importance of people signing up to Enroll-HD as it gives access to valuable information for researchers. All trials are a collaborative effort between patients, researchers and drug companies. Trials can cost between 10 and 30 million dollars.

Professor Sarah Tabrizi and **Professor Bernhard Landwehrmeyer** gave an update on Huntingtin lowering therapies and an overview of research and clinical trials. There has been an explosion of research in the last 20 years which is now at the stage of testing therapies.

Researchers believe potential treatments are currently being trialled. Huntingtin lowering therapies are among the most promising in the search for an HD treatment - targeting the production of toxic protein targets the cause of the disease. '*We know what the cause of the disease is, we know what our target is*'.

Drugs cannot cross the blood brain barrier. The brain can be reached by injecting into the spinal fluid, direct infusion into the brain ventricles via a pump or injecting into the brain tissue directly. The Huntingtin lowering IONIS trial, 1st dose was administered (via spinal fluid injection) in September 2015.

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Christmas Cards 2017

HDAI Charity Christmas Cards are available to order with new designs this year. A pack of 15 cards costs €8.00 per pack which includes postage. Let us know if your local Post Office or shop sells charity cards.

To order, email:
info@huntingtons.ie

EHA Conference (continued)

So far there are no safety issues (10 years of animal testing has been completed) with the 46 trial participants. Trial results are expected in early 2018. It is hoped to take this trial to a large phase 3 trial soon.

Prof. Landwehrmeyer said it was a time of exciting science with many approaches to finding a therapy. These include: Vector - a virus for carrying treatments, suppressing the mutant HD gene copy by targeting DNA and Zinc finger coupled to a repressor programmed to targeting CAG. Possible future research ideas might include utilising our own bodies repair mechanism to get the DNA repair machine to repair the mutant DNA to prevent onset. He finished the session with an inspirational quote *"the route to success is to go from failure to failure with undiminished enthusiasm"*.

Amy Merkel Yoga Teacher and HD family member gave a yoga and mindfulness in practice class. **Rodolfo Vera** also from a HD Family and a physical activity teacher encouraged us to be active.

Dr Jennifer Hoblyn gave a presentation on Bloomfield Health Services HD Service and their hopes for future service development.

She also delivered a presentation on *"Minding your Mental Wellbeing in HD"* and the importance of recognising one's own needs in order to be supportive as a family member or health professional. Susan O'Neill Senior Physiotherapist at Bloomfield discussed the importance of physical activity.

Dr. Klempir and **Angela Nuzzi** gave a presentation on nutrition. They stressed that keeping a healthy weight can be a big challenge for HD patients and their carers. If a HD patient becomes malnourished this can lead to many complications including:

- Reduces physical resistance
- Reduces mental endurance
- Causes and exacerbates fatigue and apathy (staying in bed longer can lead to bed sores)
- Causes complications in the course of acute and chronic diseases
- Prolongs any stay in hospital
- Prolongs recovery and increases mortality

There are many compounds on the market which contain the requisite daily need of fat, protein, minerals and vitamins. Alternatively, the use of a PEG Tube can address many of the nutritional needs of a HD patient.

Tim McLean EHDN Clinical Operation Manager stressed the importance and the opportunities of Enroll-HD. Enroll-HD is a worldwide observational study for HD families and is open to people who have HD, spouse/partners, people at-risk and HD gene negative family members. Enroll-HD helps with recruitment into clinical trials and can improve clinical care by identifying best care practices.

Jimmy Pollard gave an excellent presentation on how HD masks and disguises the sufferer's true personality ('Huntington's Disguise'), but does not necessarily completely change it. Cognitive and movement characteristics, apathy or little display of emotion, OCD-like and obsessive behaviours and spatial difficulties, as well as impatience and being slow to react or respond makes it harder to see that the real person is still there.

Difficulties in recognising and reading facial expressions adds to this. Jim urged us to see through the 'Huntington's Disguise', and be patient (Hurry Up and Wait).

There were also sessions for family members and medical professionals to discuss and share their stories and the challenges faced in dealing with HD.

Supporting Mental Health & Wellbeing



Sunshine and outdoor activities increase feeling of well-being. At this time of year, as daylight hours decrease it's important to check our mood and mind our mental well-being.

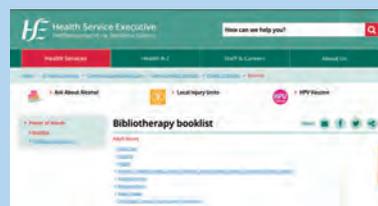
Online resources such as **YourMentalHealth.ie** provides information about mental health, and how to mind yourself and support the people you love. It provides hints on the **#littlethings** that can make a big difference to how we all feel.

Self-help books are now being recommended as a means of providing psychological therapy

'bibliotherapy' for people experiencing emotional and psychological difficulties.

Bibliotherapy has been recommended by the National Institute for Health and Clinical Excellence (NICE) UK as a useful start in treating mild and moderate depression, anxiety and panic and some other mental health problems. Psychologists and GPs working in Ireland have read and reviewed self-help books resulting in a recommended reading list compiled by Elaine Martin and Sara Kelly (HSE Primary Care Psychology, Dublin North City) in 2013.

The list includes books addressing issues including: depression, anxiety, panic, and stress and includes books useful to family carers. It is available in Public Libraries and GP clinics and online at:



http://www.hse.ie/eng/services/list/4/Mental_Health_Services/powerofwords/booklist/bibliotherapybooklist.html

When HD Came To Tea

A radio documentary on HD in Ireland has been made by producer and presenter Peter Grogan along with editor and recordist Ken Tuohy.

The one hour long programme explores this 'hidden' disease in Irish society which affects hundreds of families. The programme features interviews with those affected by HD and up to date research in the search for effective treatments.

Tune in to 'When HD Came To Tea' which will be broadcast by Dublin City 103.2 Fm on Wednesday 29th November 2017 at 3.00pm

HDAl receive media requests from time to time - If you haven't already done so but are interested in speaking to the media please let us know.

Joe Doran's HD Awareness Walk

There was a wonderful turnout for Joe Doran's HD Awareness walk at Lough Key Forest & Activity Park, Co Roscommon in July. A huge thanks to Joe, Pauline and Anne Doran, Joe (snr) and Mary Doran, Pauline's extended family and their friends. We were delighted with the great gathering from the Huntington's community (family and friends) who travelled from counties including:



Longford, Mayo, Sligo, Roscommon, Leitrim, Galway, Limerick, Kilkenny and Dublin to take part. The walk raised a magnificent €12,803 for HDAI. Sincere thanks to all who donated and raised sponsorship.



Donations included: Joe & Mary Doran £1,000, J. Coffey Construction Ltd €5,000, Bigwood Properties Ltd €1,000, Tommy and Pauline Reilly €500, Mary Dennany and friends €175, PJ and Kay O'Toole €155 (in lieu of anniversary gifts) and Peggy and Phil Fogarty and friends €220. Anne, Pauline and Frances Hughes worked hard taking registrations and

keeping track of collections. We were treated to beautiful music from musicians Aoife Guihen (flute) and Elizabeth Earley (fiddle) who kept us entertained prior to walking. Lough Key is a great location and we hope to walk again in July 2018 - we'd love to see you there!



Joe with Beccy and Darren at Lough Key



Fundraising Thank You

Dublin Mini-Marathon



We continued to receive funds from our wonderful mini-marathon participants: Bernadette and her family donated €322, Charlotte T raised €135 and Shannon Hayes (left) raised €195.

Wicklow Charity Cycle



A big thank you to Tarik who braved Wicklow's hills and raised over €450 for HDAI.

Recently received donations include:

- Martina, Finnola and Zil monthly Direct Debit donations.
- Rathfarnham Quaker Meeting
- Edward and Mary €100
- Cuisle: Raffle and Hoodies €580
- Donations at Cuisle

Parachute Jump

Fiona courageously completed a Parachute Jump in memory of her beloved late husband Padraig and raised over €800.



C&C Cellular

Thanks to Brendan Chambers at C&C Cellular who donated €240 for old mobiles. Special thanks to Jerome for gathering many phones.

Viking Marathon

Caroline Lamb took part in the Viking Quarter Marathon in Waterford and raised €266 for HDAI as she has a friend from a HD family.



Rock and Roll Marathon



Jane Merrigan completed the Rock & Roll Half Marathon on 13th August in Dublin City Centre.

"After spending a weekend with some truly inspirational people in Cuisle who live with the disease on a daily basis, I wanted to help raise funds and awareness for HD"

UPCOMING EVENTS

Celbridge Craft Fair



Íde and Máire Cussen will once again have a Handknits stall at the Celbridge Craft Fair on **Saturday and Sunday 24th and 25th November**, The Mill, Celbridge, in order to raise funds and awareness for Huntington's Disease.



HD ID Card

A free Huntington's ID card is available. Please send your photograph, address, phone number and an emergency contact person's phone number to the HDIA office and we will take it from there.

The articles which appear in this newsletter may not necessarily represent the views of HDIA.



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Sunrise Up Croagh Patrick

Huge THANKS to John Kelly, the Breen and Kelly family and friends and the team at Hanson Regan for a very positive Sunrise up Croagh Patrick awareness raising event. In 2016 John and friends first climbed in memory of the late Eleanor Breen "to symbolise the climb needed to put the support structures in place to help Irish patients and their families".



John recruited family, friends and colleagues at Hanson Reagan and invited charities supporting people with Parkinson's Disease and Motor Neuron Disease to join the climb in order to raise awareness for neurological charities. HDIA climbers included: Anne O'Shea Clarke, Bridie O'Shea, Moira Noone, Joan Moran, Joe Hannon, Paddy Connern, Deirdre McInerney, Tommy McCormack and Patricia.



The event raised an excellent €8,630.40. Thanks to all who contributed and raised sponsorship for the event.

The challenging climb in wind and rain served to remind us of the challenges people living with HD face on a daily basis. John and friends are planning another climb in 2018. Let us know if you want to join us.



John Kelly with Anne O'Shea Clarke and Bridie O'Shea

Follow HDIA on Social Media

Facebook: https://www.facebook.com/pages/Huntingtons-Disease-Association-of-Ireland/121707387897701?ref=br_tf

Twitter: @HDIA_ie

Thank you to our hardworking volunteers for their social media work.



Ann enjoys spending time with her pets

HDIA Support Meetings

You are very welcome to join us at our Support Meetings from 11.00am to 1.00pm on a Saturday in Cork, Mayo, Dublin and in Limerick from 10.30am. Our Family Support Officer or a HDIA representative will host the meetings. Tea, coffee and scones are provided. Contact the HDIA office on 1800393939 for more information.

DUBLIN

Nov. 4th

CORK

Dec. 2nd

MAYO

Dec. 9th

LIMERICK

Jan. 13th

This is your Newsletter - Please contact us if you wish to contribute.